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An Ethnographic Study of Palliative and End-of-Life Care in a Nigerian Hospital: Impact of Education on Care Provision and Utilization

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Abstract

Most clinicians receive little or no palliative care (PC) education. Similarly, patients and their families receive little or no information on PC. Our study explored education in PC, while examining for its impacts on service delivery and utilization from the perspective of health care professionals (HCPs), patients, and their families. An ethnographic approach was utilized to gather data from 41 participants. Spradley's ethnographic analytical framework guided data analysis. Two themes identified were inadequate HCPs' knowledge base and impact of service-users' inadequate health education. The findings show that most HCPs had no formal education in PC, attributed to the lack of PC residency programs and the absence of educational institutions that provide such education. Patients and families also conveyed poor understandings of their illness and palliation, rooted in the HCP culture of partial disclosure of information about their diagnosis, care, and prognosis. Findings suggest a cultural shift that supports PC education for professionals is required to promote realist medical approach in the care for patients with life-limiting illnesses.

Keywords

communication, culture of care, decision-making, ethnography, health education, hospital, Nigeria, palliative care education, patient education

Introduction

Palliative care (PC) helps patients die a “good death” in comfort, with their social, spiritual, and religious needs taken into account (Economist Intelligence Unit [EIU], 2015) and often in their preferred place of death (Ali et al., 2019). Receiving PC toward the end of life is an objective of health policy in many parts of the world. However, in Africa, PC education and, consequently, specialists in PC are severely limited (Clark et al., 2019; Van der Plas et al., 2020; World Health Organization, 2018). For instance, health care professionals (HCPs) in Nigeria and Rwanda were reported to have discharged their duties without formal training/education in PC (Agom, Poole, et al., 2019; Akinnyemiju et al., 2015; Uwimana & Struthers, 2007). However, some African countries such as Uganda, South Africa, Kenya, Botswana, Zambia, Malawi, and Tanzania have made progress through either developing PC educational center or implementing national PC program in conjunction with local universities (Hannon et al., 2016). However, such phenomena appear not to exist in Nigeria.

Generally, inadequate formal education of HCPs in PC has been widely reported as one of the reasons why PC has continued to be poorly developed in some of African countries such as Nigeria (Agom, Neill, et al., 2019; EIU, 2015; Van der Plas et al., 2020). This suggests that patients in Nigeria with life-limiting illnesses and their families may not be receiving adequate care to relieve their suffering and improve their quality of life because most PC professionals lack the knowledge and expertise to deal with the diversity

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of their problems. The 2015 Quality of Death Index showed that Nigeria and most other African countries are deficient in specialist PC professionals and this is especially the case where accreditation of specialist training is not the norm. In Nigeria, inadequate formal education in PC continues to exist for HCPs (Agom, Poole, et al., 2019; Eke et al., 2016; Nnadi & Singh, 2016). The factors contributing to this lack of formal education in PC and how it affects on the provision of PC are not yet investigated and are set to be explored in the current research.

PC is also concerned with helping patients with progressive life-limiting illnesses and their families, through health education, to understand their illness and its consequences. In Nigeria and most other African countries, there is an increasing need to improve the health literacy of patients and their families that are either in need of, or receiving, PC. This is because poor awareness and knowledge of PC among patients and their families can mean that they fail to engage in decision-making during their care or refuse to use this specialized service (Lakew et al., 2015; Opoku, 2014). However, patients and families are perceived to want health information (Mkwinda & Lekalakala-Mokgele, 2016; Nwankwo et al., 2013). Therefore, given the limited education and information provision available and the perceived desire for information from patients and families, the study reported in this article explored the factors affecting the provision of education and information in PC and its impact on care delivery and utilization of PC in a Nigerian hospital. As little is known about this problem, in-depth information from a single study site is valuable for theory development as a first step in the development of the evidence for change.

Method: Organizational Ethnography

To achieve our research aim, a methodological approach that facilitated observed realities and emic perspectives to capture the experiences and interpretations of the participants about cultural processes in relation to PC education was required; thus, an organizational ethnographic approach was deemed suitable (Reeves et al., 2008). Organizational ethnography is “ethnographic study, and its dissemination, of organisation and their organising processes” (Ybema et al., 2009:4). One of the central aims of organizational ethnography is to comprehend how the actors work and interact as they carry out their daily activities in an organization (Nyland, 2008). We were interested in organizational context of provision of education and information in PC and its impact on care delivery and utilization of PC in a Nigerian health care organization.

Study Setting

A hospital in south east Nigeria was purposively chosen for this study for reasons such as it rendered organized PC, which facilitated collection of useful data that revealed the

complexities of culture being studied, proximity and accessibility which promoted prolonged engagement as well as immersion during field work. This government-owned hospital charges a fee for inpatient and outpatient cancer and PC services for individuals living in the south-eastern Nigeria and its surrounding states (Agom et al., 2020).

Participant Recruitment

Participants for this study were purposively recruited based on three criteria: (a) HCPs who have acquired experience in providing PC and/or were actively involved in making decisions about care of patients with life-limiting illnesses such as cancer, (b) patients living with progressive life-limiting illnesses were receiving PC and were willing and assessed to have the capacity to provide informed consent, and (c) family members who were the key carer of the patient who was receiving PC.

Initially, all 11 members of the PC team (three doctors, a pharmacist, four nurses, two medical social workers, and a physiotherapist), cancer patients ($n = 10$), and patients' family members ($n = 10$) were recruited because they met the above criteria. Following preliminary data analysis in the field, an additional 11 HCPs from the oncology unit and the head of nursing were also identified and recruited. These additional participants provided information to clarify, enhance, and provide a deeper explanation of the emerging cultural patterns to achieve data saturation, as would be expected in ethnographic research (Spradley, 2016). Two of the HCPs dropped out for undisclosed reasons; thus, a total of 41 participants participated in the study.

Ethical Approval

Ethical approval was granted by the Hospital Research Ethics Committee with reference number NHREC/01/2008B-FWA00002458-1RB00002323. This to safeguard the participants' dignity, rights, confidentiality, privacy and anonymity, safety and well-being in keeping with principles of beneficence, nonmaleficence, and respect for autonomy. Participants were given participant information sheets explaining the aim of the study and their involvement, along with approaches for upholding confidentiality and anonymity. Written informed consents were obtained from the participants prior to data collection.

Data Collection Process

Participant Observation and Informal Interviews During the Observation

Participant observation provides insight into the symbolic language and interactions among the participants and improves the authenticity of the data (DeWalt & DeWalt, 2011). Descriptive, focused, and selective participant observations

Table 1. Sample of Interview Questions.

Descriptive questions	Structural questions	Contrast question
<ul style="list-style-type: none"> • Can you tell me about palliative care education among the professions? • Can you tell me about provision of information/ health education to the patients and their families about their illness and care? • Please, tell me about your illness and care? • Please tell me about the illness and care of your family member? 	<ul style="list-style-type: none"> • Please can you tell me more about: • Your formal training/ education in palliative care? • Educational training and qualifications in palliative care for other professionals involved in care of these patients? • Information provided to you about your illnesses and plans for your care? • Information provided to you about the illnesses and care of your family member? 	<ul style="list-style-type: none"> • Can you tell me changes in your knowledge of this illness now you are in the hospital and prior to receiving care here?

Table 2. Sample of domain analysis worksheet.

Included terms	Semantic relationship	Cover term
In-service palliative care training Desire for formal training in palliative care No institution for palliative care training I have no certificate in palliative care I do this work with no formal education No paper qualification to post nurses No residency programme in palliative care Only two nurse had short formal training	Is a form of issues related to	Formal training in palliative care

were conducted by the first author in the PC unit and the oncology department of the studied hospital in line with Spradley's framework for participant observation (Spradley, 2016). The lead author (D.A.A.) adopted the role of a nurse and took a participant-as-observer stance during observation because it enabled in-depth an understanding of cultural rules for actions about the provision of education and information in PC and its impact on care delivery and utilization. Participant observation was conducted in seven wards, the PC and oncology outpatient clinics, the PC nurses' station and meetings between the patients' family members and the PC team. Observations were conducted during morning, evening, and night shifts and lasted more than 8 hr in each observation period, 3 days a week for 24 weeks. Data were recorded in a condensed field note during observation, followed by expanded account and fieldwork journal at the end of daily observation as recommended by Spradley (2016). Informal conversation with the participants was also undertaken to clarify what was observed. Overall, 687 hr of the participant observation was completed; 445 hr initially between September 2015 and March 2016 but following preliminary analysis of the data, a further 242-hr observation was achieved between March 2017 and May 2017 to attain data saturation.

Interviews

Spradley's framework for an ethnographic interview (Spradley, 2016) was utilized during semi-structured face-to-face interviews with 41 participants. The interview offered opportunity for a more relaxed and in-depth conversations to

learn and clarify issues about the behavior and activities observed around the culture of PC education, enhancing the understanding of the context and intentions behind the observed behavior and practices. Interviews were discretely conducted by the lead author in the meeting room, offices, or patients' bedside at their convenient time. First, descriptive questions were asked to elicit descriptions of PC education, health education, and experiences of delivering/receiving care. These questions were followed by what Spradley regarded as structural questions (questions uncovering more information about domains and how interviewees organized their knowledge; Spradley, 1979). Third, contrast questions focusing on the contrast in meaning about the education were asked. The sample of each category of interview questions is shown in Table 1. Interviews lasted between 45 and 90 min and were digitally recorded and transcribed verbatim.

Data Analysis

Domain, taxonomic, componential analyses, and the discovery of cultural themes, consistent with Spradley's framework for ethnographic data analysis (Spradley, 2016), were conducted by the first author but reviewed by coauthors to ensure accuracy. During the domain analysis, NVivo qualitative data analysis software; QSR International Pty Ltd. Version 11 aided reduction of an extensive rich dataset into what Spradley termed "include terms," and cover terms. Thereafter, a search for semantic relationships was done by constructing Spradley's domain analysis worksheet. Sample is shown in Table 2.

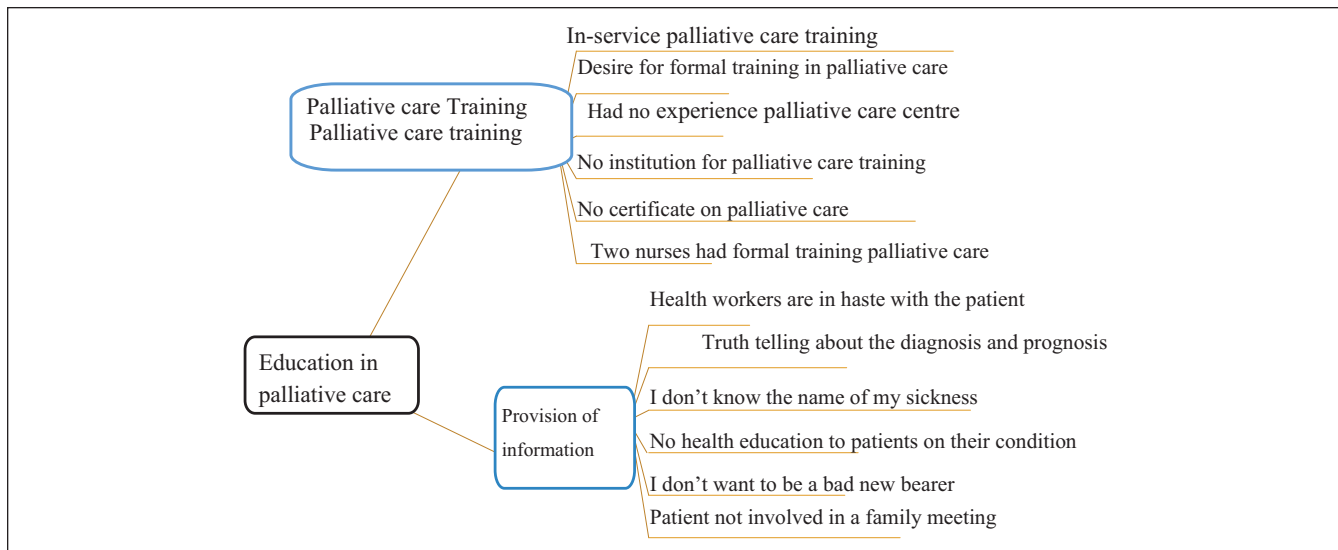


Figure 1. Sample of taxonomic analysis.

Table 3. Sample of Paradigm Worksheet Using Cultural Categories of Education in Palliative Care.

Education in palliative care	Domain (cultural category)	Dimensions of contrast	
		Formal training in palliative care	Provision of information to patients and families
	Doctors	No	Yes (some)
	Nurses	Yes (some)	Yes (some)
	Pharmacist	No	No
	Physiotherapists	No	No
	Social workers	No	Yes (some)

Second, a taxonomic analysis was done by searching for relationships existing among the domains which were organized based on single identifiable semantic relationship to form distinctive taxonomies (see Figure 1).

Third, during componential analysis, all the contrasts or components of meanings associated with several taxonomies were searched and organized using what Spradley named a “paradigm worksheet” (see Table 3).

Finally, the relationships that existed among the taxonomies were examined by arranging those that are similar, to form single ideas, thereby arriving at two cultural themes: inadequate HCPs’ knowledge base and impact of service-users’ inadequate health education.

Rigor

It has been highlighted that the trustworthiness criteria for ethnography are under contentious (Hammersley, 1998). Therefore, standards for assessing qualitative research were applied in this study. First, persistent observation and prolonged engagement in the field provided opportunities to understand hidden dimensions and emic perspectives (Nyland, 2008), which facilitated tacit, as well as explicit,

knowledge of the culture under study, thus enhanced study credibility. Second, explicit documented methods and analysis enabled the transferability and conformability of the study findings (Jirojwong et al., 2011). Third, the first author engaged in reflexivity all through the research process which further enhanced the study rigor. For instance, D.A.A. negotiated to work with the members of palliative/oncology team as a nurse because of his previous training and experiences working as a nurse. He therefore worked as a nurse-ethnographer researching a study site and with staff unfamiliar to him. Although this unfamiliarity helped him to maintain detachment and the critical eye required during ethnography, his clinical nursing background was sufficiently similar to provide him with some implicit assumptions and knowledge regarding culture of education. In addition, D.A.A. being born in the geopolitical region where the study site is located, he acknowledges that his background will inevitably have influence throughout the fieldwork, interpretation, and knowledge construction. However, reflexive practice and collaboration with coauthors to discuss the ongoing fieldwork and to confirm field analysis, mitigated bias, enhanced accuracy, and credibility of the findings.

Findings

The two themes generated following data analysis are inadequate HCPs' knowledge base and impacts of service-users' inadequate knowledge. These themes are discussed below.

Theme 1: Inadequate HCPs' Knowledge Base

Competency in PC could be attained through formal theoretical teaching and mentored clinical exposure, but very little formal PC education among the HCPs was identified in the data as indicated in the following extract:

Only two nurses among all the members of the palliative care team received six weeks training in palliative care at Uganda. (PC Doctor 1)

According to HCPs, PC was being delivered by a team who lacked specialist knowledge and were therefore not necessarily competent to provide PC. Rather, their involvement with the care of patients with life-limiting illnesses was based on what some participants regarded as a "mind qualification" (on the basis of individuals who are compassionate and empathic to patients and their family members) and personal interest:

I consider mind qualifications as criteria for dispatching nurses to palliative care or oncology units. I mean staff I considered having the ability to work and have heart to care for this group of patients. (Head of Nursing)

I am employed to work in another department but I volunteered to work in palliative care unit because of my interest in palliative care. (PC Doctor 1)

Arguably, "mind qualifications" and/or individual interest appeared to be used as a substitute for academic qualifications due to lack of formal education in PC. Generally, the HCPs attributed their lack of formal education in PC to the absence of training institutions that provide such education, and the lack of PC residency programs in Nigeria:

There is no curriculum or institution in Nigeria for training healthcare workers in palliative care. (Nurse 2)

There is no residency program in palliative care in this country. We are waiting for our "big ogas" to start it. (PC Doctor 1)

It seems that PC education is not yet integrated into the undergraduate and postgraduate educational curricula in Nigeria. Some participants recognized the importance of such education but felt powerless to establish it, instead perceived that the "big ogas" (which symbolically means health and education policymakers) who possess power lacked commitment to set up PC residencies and other PC educational programs. Interestingly, most of the HCPs expressed a

desire for PC education, but were hampered by the lack of local training opportunities and the inability to afford the cost of such education abroad:

I have a passion for formal education in palliative care but there is no institution that offers such training in Nigeria. I have no fund to travel abroad for such education. (PC Doctor 2)

The lack of PC training institutions in Nigeria could mean that the majority of clinicians involved with the care of patients with life-limiting illnesses in the study hospital, and other hospitals in Nigeria, are not adequately knowledgeable about the unique physical, spiritual, and psychosocial needs of service-users throughout their disease trajectory, thereby making it difficult to meet those, often challenging, needs. The lead author repeatedly observed that most of the professionals were ill-prepared to provide PC as demonstrated in their being in a rush during ward rounds, not engaging patients or their families in a discussion about the illness and the care, and not providing care to patients perceived to be stable. Field notes suggest this:

... the team immediately moved to another patient's bedside but the doctor said there was no need to provide palliative care to the patient because he was still stable and relatively active. (Field note, F26)

The team did not hold a conversation with patients' relatives ... left ward 10 to go to the oncology ward. (Field note, F9)

The observation data indicate an organizational context whereby poor educational provision and inadequate training for HCPs contributed to why some patients and their families who seek care in the study hospital had experienced unmet PC needs. This is explored in the following cultural theme.

Theme 2: Impact of Service-Users' Inadequate Health Education

The service-users reported that clinicians did not provide any information about their condition; consequently, they lacked understanding about the illness, including the aim of their treatment:

The doctors mostly asked me if I have a new complaint, thereafter, they speak to themselves, not explaining what they are doing. (Patient 1)

... We do not know the name of this illness and what to expect. (Patient Relative 3)

Patients and families expected information from the clinicians but conveyed a lack of understanding of their illness and palliation because even basic information about their diagnosis, prognosis, and management was not provided. These extracts could also indicate organizational hierarchical culture in which the HCPs appear not to encourage the

patients and their families to participate in discussions and decision-making about their care. However, some participants disclosed that while they had been told about their diagnosis and the management of their illness, the information provided was not sufficient to understand their illnesses and plan for the future. For instance,

The doctors explained the management, but no information about the possible outcome was provided to me. Again, the doctors refused to provide an answer to my question of whether chemotherapy will cure the illness . . . (Patient 10)

I was told by the doctor that I have cancer, but I did not understand what that means. (Patient 3)

Partial provision of information to the service-user appeared to be a dominant organizational practice embedded in the delivery of PC at the studied hospital. This suggests that most of the service-users may have had an unmet need for information influencing their knowledge/understanding of their illness and palliation. It may be that this lack of knowledge and understanding explains why most service-users did not participate in decision-making about their care, as observed repeatedly during PC routines:

The doctor and other members of the palliative care team agreed to request an abdominal tap for the patient and to explore possibilities for surgery, but neither the patients nor their families were involved in these discussions. (Field notes, F73)

Some HCPs stated that health education was only partially provided to service-users, corroborating the views of patients and their families:

We, the doctors do not provide adequate health education to the patients and their families. We mostly avoid the provision of information about diagnosis and prognosis to avoid being bad news bearers . . . (Oncology Doctor 1)

The extract above could indicate that some HCPs feared being labeled a “bad news conveyor,” thus protecting themselves rather than their patients. This, in turn, may have deterred them from providing health education concerning diagnosis and prognosis. The more remarkable finding was that HCPs stated that the practice of withholding information could prevent service-users from requesting self-discharge against medical advice:

If you provide adequate health education to the patient on their illness, they will run away and will assume that you have pronounced death upon them . . . (PC Doctor 1)

Health professionals could then justify the practice of withholding information since withholding or giving only partial information helps to keep patients under hospital care which could paradoxically improve their health outcomes or the quality of the dying process but also that they pay more.

In addition, some HCPs felt that neglecting to provide adequate health education to the patients and their family members could prevent psychological or emotional distress:

We do not educate patients about their diagnosis and prognosis, though we sometimes communicate this information to their relatives because informing patients will worsen their emotional and psychological distress. (Oncology Doctor 2)

The clinicians presented the view that withholding information on compassionate grounds protects patients’ psychological security. Surprisingly, some patient’s relatives supported this partial health education, by concealing information provided to them by the clinicians from their ailing family member to protect their psychological well-being:

The doctor told that my sister has enlarged liver and cancer but we do not let her know about it because we feel that informing her will make her to be depressed and worsen the condition. (Patient Relative 5)

The principle of beneficence was used to justify the cultural norm of partial health education, in that some clinicians, as well as family members, concealed information from the service-users to foster hope and to reduce the perceived psychological distress that “bad news” would cause to the patients.

Discussion

The majority of the HCPs were found to lack formal education in PC with the associated impact on the provision and use of PC. For instance, the professionals’ lack of education in PC appeared to have contributed to their lack of knowledge and skills to effectively communicate and educate the patients and their family members about their illness and palliation. It promulgated a practice based on false assumptions concerning the impact of aspects of care such as patient education. The absence of training institutions for PC was consistently stated by the HCPs in the current study as the cause of the lack of formal education, which was perceived to be rooted in a lack of willingness of the political leaders who possess power to establish such training in Nigeria; this requires further investigation. Other researchers in Nigeria have also acknowledged the absence of PC training institutions/universities in Nigeria (Oyebola, 2017). In addition, a previous study conducted in Lagos State in the south-west of Nigeria found that HCPs involved with the care of cancer and HIV patients had learned some aspects of PC on the job without any formal training (Akinnyemiju et al., 2015). This suggests that the absence of formal PC education for HCPs is not peculiar to the studied hospital. Overall, inadequate formal PC education reinforced clinicians’ lack of specialist knowledge, thus providing an explanation for some HCPs’ lack of preparedness to provide PC in this research reported here.

The HCP's lack of formal education in PC was found to underline the dominant culture of partial provision of health education to patients with life-limiting illnesses and their families in the studied hospital. This practice was based on the two informal cultural rules that were HCPs self-protection motive demonstrated through avoidance of being the bearer of bad news and as an approach to avoid psychological or emotional distress for the patients and their families. Previous literature suggests some disagreement as to whether providing information will cause issues for the patients. For instance, the findings by Smith et al. (2010) and Enzinger et al. (2015) do not support the idea that disclosing prognostic information or providing enough information to patients and their relatives to enable them to understand their illness and care options will degrade patients' hope, or increase anxiety and depression. However, Yoshida et al. (2012) argue that prognostic information may generate some psychological distress. A more disconcerting finding about the partial provision of health education was that this culture could be interpreted as a deliberate practice rooted in power imbalance and aimed at retaining patients and thereby increasing the financial benefit to the hospital. This is because when patients are retained for care, they continue to pay for the services they are receiving. Payment for health care services is the key financial mechanism operational in the Nigerian health care system (Agom et al., 2020; Aregbeshola & Khan, 2018).

Second, the modern medical practice supports the principle of respect for patient autonomy, which is associated with providing enough information to the patients for them to participate in decision-making (Beauchamp et al., 2013). This is a fundamental principle underpinning informed consent to treatment. However, patients and their families in the current study were deprived of adequate information (health education), which prevented them from participating in decision-making about their care because they had inadequate knowledge of their illness and the possible care options. This portrays culture of hierarchical power relations in which the HCPs appeared to have either consciously or unconsciously exercised power over the patients and their families during information provision. Instead, treatment and care decisions were largely made by the clinicians, a practice suggestive of medical paternalism (Steinbock, 2007). Medical paternalism is argued to be justifiable, on the basis that it prevents patients' irrational decisions while empowering the physicians and other HCPs who possess the knowledge and experience to make decisions and act for the patients' own good (Ayodele, 2016; Conly, 2014). Conversely, the argument against medical paternalism is that it denies patients' the right to make choices, violates the right of patients to make decisions about their own health care, countermands person-centered care, and could promote the abuse of power (Beauchamp et al., 2013). It can be argued that paternalistic practice is currently embedded in the day-to-day practices of PC delivery in the studied hospital. This can be perceived as culturally sensitive practice because the patients, their relatives, and the clinicians seem to support partial disclosure of

information about death and dying, an indication of a culture that may not be ready for a complete transition to a western cultural practice of acceptance to receiving or providing full information in end-of-life care as well as preparedness to managing the consequences of such full disclosure. Alternatively, paternalistic approach to PC delivery in the studied hospital could be an indication that realist medical approach is required. A concept that is pertained to care relationship whereby HCPs and service-users can share in power and responsibility of decision-making to promote patient's participation by empowering them to share their beliefs, values, and preferences (NHS Scotland, 2015).

Strengths and Limitations

Persistent and prolonged observations, as well as the use of other methods of data collection, are the strengths of this study because it facilitated an in-depth understanding of the culture of education, which has provided theoretical knowledge relevant for analytical and theoretical generation of the findings. Although use of one study site was a limitation because the findings may not fit population generalizability, but concentrating on one hospital allowed the complexities of issues to be revealed in context with accomplished improved learning which will aid understanding of many other similar contexts, thus holding value with respect to situational and conceptual generalizability (Leung, 2015; Popay et al., 1998). Again, this study does not capture reasons for the perceived lack of commitment by the policymakers to establish formal PC education.

Implications

This research revealed that organizational power hierarchies, lack of or limited PC education create situations where HCPs do not reveal important information to patients to protect themselves, as well as to avoid upsetting patients and families through such difficult conversations. This suggests that patient autonomy may not be well considered by HCPs in an environment where there are inadequate PC education and power imbalance in care relationship. This finding can be used as a reference point to develop continuing professional development training to professionals in various hospitals in Nigeria and other countries with no or limited institutions that provide formal PC education, on how to communicate sensitive and difficult information to patients and families and to develop hospital guidelines/policy on how to ensure patient autonomy. This article also provides information at a more general level as to why medical paternalism has continued to be practiced in the Nigerian health care system, suggesting that policy actions are urgently required in the area of PC education and continuing professional development to enable clinicians to change culturally based style of doctors know it best to a collaborative or relational decision-making approach in the care for terminally ill and dying patients.

Furthermore, this article has highlighted the need for improvements in funding and advocacy for PC education in Nigeria and other African countries. This will contribute toward increasing the limited PC workforce, especially in the African continent to make this specialized service available for all in a manner that will improve the quality of life of patients and their families.

Conclusion

This research showed for the first time that a medical culture was built on a lack of educational opportunities to study PC and hence, a culture of care had developed that makes the delivery of PC difficult and antagonistic to person-centered care. This lack of educational opportunities stemmed mainly from a sociopolitical culture that is “auto-inhibitory” to PC, in that the political class was perceived to lack the drive to support the needed improvement in PC practice, such as the establishment of PC training programs, thus leading to poor knowledge and ill-preparedness of the professionals for PC. The provision of PC was rooted mainly in medical paternalism, which created an income stream for the studied hospital. Specifically, this study contributes a new understanding that palliative and oncology care may not thrive in any society whereby subjugation of patients and their families in participating in clinical decisions has been tacitly accepted as a norm and whereby health and social policymakers lack the determination to support PC education and training. Future research should explore the intricacies of formal education in PC from the perspectives of policymakers and medical professional bodies as well as the level, impact of PC formal education and continuing professional development courses, and the impediments to PC financing by the public or private sector.

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References

- Agom, D. A., Allen, S., Neill, S., Sixsmith, J., Poole, H., Onyeka, T. C., & Ominyi, J. (2020). Social and health system complexities impacting on decision-making for utilization of oncology and palliative care in an African context: A qualitative study. *Journal of Palliative Care*, 35, 185–191.
- Agom, D. A., Neill, S., Allen, S., Poole, H., Sixsmith, J., Onyeka, T. C., & Ominyi, J. (2019). Construction of meanings during life-limiting illnesses and its impacts on palliative care: Ethnographic study in an African context. *Psycho-Oncology*, 28(11), 2201–2209.
- Agom, D. A., Poole, H., Allen, S., Onyeka, T. C., & Ominyi, J. (2019). Understanding the organization of hospital-based palliative care in a Nigerian Hospital: An ethnographic study. *Indian Journal of Palliative Care*, 25(2), 218–223.
- Akinnyemiju, Y., O'Connor, T. L., Salako, O., Jimoh, M., & Nwogu, C. E. (2015). Palliative care awareness among health care professionals in Nigeria. *Journal of Clinical Oncology*, 33, e20548. https://doi.org/10.1200/jco.2015.33.15_suppl.e20548
- Ali, M., Capel, M., Jones, G., Jones, G., & Gazi, T. (2019). The importance of identifying preferred place of death. *BMJ Supportive & Palliative Care*, 9, 84–91.
- Aregbeshola, B. S., & Khan, S. M. (2018). Out-of-pocket payments, catastrophic health expenditure and poverty among households in Nigeria 2010. *International Journal of Health Policy and Management*, 7, 798–806.
- Ayodele, J. A. (2016). The realities surrounding the applicability of medical paternalism in Nigeria. *Global Journal of Social Sciences*, 14, 55–61.
- Beauchamp, T. L., James, F., & Childress, J. F. (2013). *Principles of biomedical ethics* (7th ed.). Oxford University Press.
- Clark, D., Baur, N., Clelland, D., Garralda, E., López-Fidalgo, J., Connor, S., & Centeno, C. (2019). Mapping levels of palliative care development in 198 countries: The situation in 2017. *Journal of Pain and Symptom Management*, 59, 794–807.e4.
- Conly, S. (2014). Against autonomy: Justifying coercive paternalism. *Journal of Medical Ethics*, 40, 349.
- DeWalt, K. M., & DeWalt, B. R. (2011). *Participant observation: A guide for field work* (2nd ed.). AltaMira Press.
- Economist Intelligence Unit. (2015). *The 2015 Quality of Death Index Ranking Palliative care across the world*. www.eiuperspectives.economist.com/healthcare/2015-quality-death-index
- Eke, G. K., Ndukwu, G. U., Chukwuma, N. S., & Diepiri, B. B. (2016). Knowledge and perception of healthcare providers towards palliative care in Rivers State, Nigeria. *Port Harcourt Medical Journal*, 11, 156–160.
- Enzinger, A. C., Zhang, B., Schrag, D., & Prigerson, H. G. (2015). Outcomes of prognostic disclosure: Associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer. *Journal of Clinical Oncology*, 33, 3809–3816.
- Hammersley, M. (1998). *Reading ethnographic research: A critical guide* (2nd ed.). Longman.
- Hannon, B., Zimmermann, C., Knaul, F. M., Powell, R. A., Mwangi-Powell, A., & Rodin, G. (2016). Provision of palliative care in low- and middle-income countries: Overcoming obstacles for effective treatment delivery. *Journal of Clinical Oncology*, 34, 62–68.
- Jirojwong, S., Johnson, M., & Welch, A. (2011). *Research methods in nursing & midwifery: Pathways to evidence-based practice*. Oxford University Press.
- Lakew, S., Musema, H., Shimeles, T., & Challinor, J. (2015). Assessment of knowledge, accessibility and utilization of palliative care services among adult cancer patients at Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia, 2014: A cross-sectional institution based study. *BMC Research Note*, 8, Article 657.
- Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Journal of Family Medicine and Primary Care*, 4, 324–327.
- Mkwinda, E., & Lekalakala-Mokgele, E. (2016). Palliative care needs in Malawi: Care received by people living with HIV.

- Curationis*, 39, a1664. <http://dx.doi.org/10.4102/curationis.v39i1.1664>
- NHS Scotland. (2015). *Chief medical officer's annual report 2014-15 realistic medicine*. <https://www2.gov.scot/Resource/0049/00492520.pdf>
- Nnadi, D. C., & Singh, S. (2016). Knowledge of palliative care among medical interns in a tertiary health institution in North-western Nigeria. *Indian Journal of Palliative Care*, 22, 343–347.
- Nwankwo, K. C., Anarado, A. N., & Ezeome, E. (2013). Attitudes of cancer patients in a university teaching hospital in southeast Nigeria on disclosure of cancer information. *Psycho-Oncology*, 22, 1829–1833.
- Nyland, D. (2008). *Organizational ethnograph*. SAGE.
- Opoku, J. K. (2014). Health and care development: An exploration of factors that hamper better palliative care in Sub-Saharan Africa. *European Journal of Biology and Medical Science Research*, 2, 1–16.
- Oyebola, F. O. (2017). Palliative care trends and challenges in Nigeria—The journey so far. *Journal of Emergency and Internal Medicine*, 1, 17.
- Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8, 341–351.
- Reeves, S., Kuper, A., & Hodges, B. D. (2008). Qualitative research methodologies: Ethnography. *British Medical Journal*, 337, Article 1020.
- Smith, T. J., Dow, L. A., Virago, E., Khatcheressian, J., Lyckholm, L. J., & Matsuyama, R. (2010). Giving honest information to patients with advanced cancer maintains hope. *Oncology*, 24, 521–525.
- Spradley, J. P. (1979). *The ethnographic interview*. Holt, Rinehart and Winston.
- Spradley, J. P. (2016). *Participant observation*. Waveland Press, Inc.
- Steinbock, B. (2007). *The Oxford Handbook of bioethics*. Oxford University Press.
- Uwimana, J., & Struthers, P. (2007). Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 4, 575–585.
- Van der Plas, W. Y., Benjamins, S., & Kruijff, S. (2020). The increased need for palliative cancer care in Sub-Saharan Africa. *European Journal of Surgical Oncology*, 46, 1373–1376. <https://doi.org/10.1016/j.ejso.2020.03.212>
- World Health Organization. (2018). *Palliative care: Fact sheet*. <http://www.who.int/news-room/fact-sheets/detail/palliative-care>
- Ybema, S., Yanow, D., Wels, H., & Kamsteeg, F. H. (Eds.). (2009). *Organizational ethnography: Studying the complexity of everyday life*. SAGE.
- Yoshida, S., Shiozaki, M., Sanjo, M., Morita, T., Hirai, K., Tsuneto, S., & Shima, Y. (2012). Pros and cons of prognostic disclosure to Japanese cancer patients and their families from the family's point of view. *Journal of Palliative Medicine*, 15, 1342–1349.